

*Physical Disabilities
Through the Lifespan*



Childhood Neurological Disorders

July 22, 2003

Physical Disabilities Through the Lifespan



State of the Field

- This session examined the following childhood disorders: cerebral palsy, spinal cord injury, epilepsy, brachial plexus injury at birth, spina bifida, and muscular dystrophy.
- Some of the disorders we discussed occur uniquely in childhood (e.g., genetic disorders, cerebral palsy), while some also occur during adulthood (e.g., spinal cord injury). When onset begins in childhood, the disorders express themselves somewhat differently, have long-term consequences, and often create a high risk for secondary disabilities.

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Problems/Concerns/Issues

- There is a lack of continuity of care between child-serving systems and adult systems. Children often come from multidisciplinary settings and are dumped into uncoordinated adult systems characterized by individualized specialty care.
- Children with disabilities often develop secondary impairments over time as they age. There is a need for knowledge, programs, and interventions that can minimize the impact of these secondary conditions.
- There is concern about obesity and a sedentary lifestyle for many of these children, particularly the impact on developing further impairment.

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Research Priorities

- Establish multicenter collaborative networks to study children with disorders over time to understand natural history, commonalities, impact of interventions, as well as unique characteristics of each childhood disorder.
- Create pilot programs with built-in evaluation on transition to adult services which would study children with disabilities as they enter the adult arena.
- Study children with common issues due to their sedentary lifestyle irrespective of their disabilities (e.g., obesity and pain). Examine the consequences of these secondary disabilities and preventive interventions.
- In addition, there were a number of disorder-specific research questions proposed (e.g., the need to study epilepsy in children as most epilepsy studies focus on temporal lobe epilepsy, which is rare in children).